

## **The Governor's Advisory Council on Pain and Symptom Management Town Hall Meetings**

In accordance to Chapter 192.350-192.355 RSMo, the Governor's Advisory Council on Pain and Symptom Management held town hall meetings during the months of September and October, 2004. Comments were received from victims of chronic and/or acute pain, health care providers, and health care educators. To follow are the major categories in which the comments have been grouped, as well as summaries of those comments. The Council wishes to thank all of those individuals who helped make these meetings possible and those who shared their stories with us.

### **Provider and Consumer Education**

Lack of healthcare provider knowledge regarding pain assessment and management was identified by the majority of individuals as a primary barrier to proper pain care. Failure to provide information in curriculum of schools of medicine, nursing, pharmacy, and others, as well as a lack of continuing education are cited as critical problems. Pain is one of the most universally experienced phenomenon and yet healthcare providers practice with many misconceptions about pain, a lack of understanding that uncontrolled acute pain increases the risk for developing persistent debilitating pain, fear of prescribing opioid pain medications despite available guidelines and policies, and a lack of knowledge regarding the need for an interdisciplinary approach to care.

Participants suggested the following solutions: curriculum changes to include pain pathophysiology, assessment and management; mandatory continuing education; education of healthcare providers on the difference between addiction and physical dependence; increased awareness of state and federal guidelines, and standards and statutes supporting the diagnosis and treatment of pain as an integral component to the practice of medicine.

Many of the individuals providing testimony identified a lack of consumer knowledge regarding a right to optimal pain therapy and failure to understand the consequences of untreated pain as a factor in the pain epidemic. Suggestions included a need to increase consumer awareness of the incidence and tragedy of untreated pain, education on patient rights, improved healthcare provider/patient communication and education on the difference between addiction and physical dependence. Patients and families need to be empowered to take a more active role in their care.

### **Vulnerable populations**

Town hall attendees voiced the common perception that all persons in pain are a vulnerable group. Comments included: "Pain victims have to fight for everything they get;" "Going on disability is a stigma – doctors treat you differently;" "If you don't look sick, you aren't believed, and it's harder to get care." These and other comments reflected a general sense that, because pain is a subjective phenomenon, people who report it are subject to a set of negative stereotypes that interfere with treatment.

Within the above context, several patient groups were identified who appear particularly vulnerable to under-treatment. One such group is comprised of elderly persons. Their risk for under-treatment may reflect, in part, a tendency to downplay pain: "The elderly tend to suck it up and don't seek pain relief." Other factors also play: "Elderly people are sometimes treated as

throwaways;” “Elderly patients don’t have a good support system for advocating for them.” Other comments noted the medical complications that often attend elderly patients, making them more difficult to treat. Residents of nursing homes were singled out by many as especially at risk for under-treatment: “When the person is transferred to long term care (LTC), the pain control is not the same;” “Need more training for med techs in LTC to identify when pain medication might be indicated for residents that cannot communicate their needs.”

On the other end of the life spectrum, children are another vulnerable population. Many myths, such as “children don’t feel pain,” lead to under treatment of pain. One of the town hall participants was a father of a child with cancer who reported that “children don’t get the same level of care for treatable and non-treatable cancer.”

Another at-risk group includes those with psychiatric problems. Numerous comments addressed the fact that psychiatric problems frequently occur when pain is poorly controlled. “People just put up with you;” “It’s hard to see light at the end of the tunnel...” Psychiatric problems appear to cut two ways. First, pain-related symptoms often are discounted when people who have mental health problems report them. Second, mental health problems often go untreated. Aside from general mental health problems like depression and anxiety, issues associated with the use of controlled substances are particularly problematic. Numerous participants commented on difficulty obtaining analgesics when needed: “Patients may know there is a medication that works for them, but they can’t get it.” To some degree, they attributed the unavailability of appropriate medications to misuse by some persons: “Many people who have life problems try to deal with them by using pain meds.” To a greater degree, however, they attributed the unavailability to physician reluctance to prescribe opioids, even when indicated for the treatment of severe pain: “Many disability patients are assumed to be drug seeking;” “There is over concern about addiction.” Access to pain medications and opioids are not always easily accessible in rural and/or smaller pharmacies. It may take a couple of days to fill a prescription. Pharmacies may not have enough medications on site to fill a one-month supply. Some pharmacists are unwilling to fill these prescriptions.

While several other vulnerable groups were identified, one received greater attention than others: people involved in Workers’ Compensation. Several participants reported that pain treatment is particularly problematic in the Workers’ Compensation system: “The Workers’ Comp system is a problem;” “Workers’ Comp doesn’t see how many problems are related to pain.”

### **Funding**

Many of the individuals who commented had concerns about the limited funding or lack of funding for chronic pain management. Medicaid and Medicare patients find it difficult to receive the broad range of care that may be necessary to effectively manage pain. Specialty services such as extended physical and/or occupation therapy, massage therapy or chiropractic care, are seldom covered by these government programs. New and innovative technology that can assist in the reduction of pain such as alpha stimulation is not covered by Medicare or Medicaid. “It is hard to find a physician that is willing to care for MC + patients (with chronic pain),” stated one of the meeting’s presenters who has suffered pain for many years.

Private insurance also has its limitations when it comes to coverage to adequately care for pain victims. Experts in pain management (pain consultants) are usually not covered; frequent changes in medications require co-pays and possible denials of coverage; and many companies require specific diagnosis by specialists prior to obtaining necessary equipment for pain stimulators or pumps. Identifying a specific diagnosis/etiology is not always possible with pain.

Failure to adequately address chronic pain has a huge impact on an individual's finances, and in turn, the economy of the state. Chronic pain can lead to increased suicide rates, family stress, loss of jobs and thus, loss of insurance. The unemployed victim of chronic pain will probably not receive the care needed. By the time that (s)he becomes eligible for Medicare or Medicaid, his/her symptoms will have worsened or be out of control, requiring more support from government programs for resolving or at least managing the symptoms.

### **Access to specialty/multidisciplinary/alternative care**

Between the geographic barriers and primary care provider reluctance to refer, many participants voiced concerns about the lack of adequate attention to debilitating pain conditions. Many participants commented about the need for access to specialty care, i.e., treatment through providers or teams of providers expressly trained in the assessment and treatment of pain. Several spoke of reluctance on the part of primary care providers to refer to pain specialty services. In rural areas, geography also complicates access to specialty care, as pain specialists are in short supply. Several participants suggested that a visiting nurses program might be an answer to the supply issue.

Comments were also provided which supported a need for a more holistic approach to addressing pain and symptom management issues. Physicians were perceived by some as lacking the time and sensitivity to address mental, emotional and social issues impacting successful management of pain. Mental health and substance abuse counselors, physical therapists, anesthesiologists, chiropractors, naturopathic and homeopathic physicians, dieticians, massage therapists and spiritual care providers were all included as desirable resources by participants. This "complementary care" is viewed as having the potential for empowering patients and families to take a more active role in care and addressing depression, anxiety, alienation and spiritual distress—factors that often aggravate pain.

In cases where complementary health providers were consulted there is usually no collaboration to ensure continuity of care. Nor is funding readily available through insurance or governmental health care programs to support these services. Several participants advocated the hospice interdisciplinary model as a viable approach to integrating holistic pain and symptom management while providing a physician supervised plan of care.

### **Transportation resources for pain and symptom management**

Transportation to doctors and specialists for diagnosis and treatment and to pick up prescriptions were among the barriers to accessibility to pain and symptom management. People in pain often do not drive due to disability or don't have cars or assistance getting to appointments. Family and friends often work during hours when appointments are most often available. Health care consumers in pain who may be wheelchair or walker dependent must use public transportation, which means long waits in uncomfortable settings or in bad weather, and limiting health care

providers to those whose offices are on the bus line. Unreliable transportation causes missed or late appointments. Physicians reportedly either refuse to reschedule latecomers or reschedule weeks or months in the future resulting in prolonged suffering for consumers whose symptoms are not yet adequately diagnosed and treated. Increasing the availability of nurses' visits to the home was recommended as a solution to some patients with transportation issues.

### **Legal issues**

Comments were submitted by health care professionals who expressed concern about how state professional licensing boards, particularly the Missouri State Board of Registration for the Healing Arts, addressed issues related to pain management. Statements were made that if a physician 'over medicated' or used significant amounts of controlled substances to address pain, those physicians were putting themselves at risk for scrutiny and possible disciplinary actions. "Physicians are afraid to adequately treat pain." Others commented that the state and federal statutes related to controlled substances are confusing and not consistently enforced across the state.